

**Celebrating
40 years!**



Huntington Society of Canada's 40th Anniversary Campaign: Grassroots to Mountaintops. Building a new chapter in our history starts now.

The Grassroots to Mountaintops campaign goal is to raise \$5 million to meet critical needs. With the help of our strategic partners and supporters, the Huntington Society of Canada continues to be an innovator by creating opportunities across Canada.

To learn more click here.

Strength & Knowledge

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Patient Friendly

Treatment algorithms can help you become a Huntington's disease "Symptom Survivor"

By LaVonne Goodman, M.D.

For most patients and families, receiving the best treatment for symptoms of Huntington's disease is challenging. Huntington's disease (HD) experts have years of experience treating HD symptoms, but most patients don't receive care from these doctors. Many patients and families live far away from specialty HD care centres; and lengthy travel becomes more difficult as illness progresses. In addition, HD experts have limits to how many patients they can effectively manage. For this reason, the majority of HD families receive most, if not all of their medical care from general physicians. These physicians often have little knowledge of specific HD symptoms, and lack of training in how to treat them. This leads to frustration for patients, families, and doctors alike. Unfortunately, this frustration may lead to the conclusion that HD symptoms are not treatable.

This "no-treatment" perception about HD needs to change.

Though we can't beat all of HD, and the drugs we have for symptomatic treatment aren't perfect, and can't "cure" the symptom - they can significantly reduce the severity of many symptoms. There are steps you can take to help your general doctor help you to be a HD "symptom-survivor"!

See page 2 for specific topics that can help.



Enroll-HD is a very exciting global initiative that is a planning and consultation process for clinical trial registration for Huntington disease.

Publications and fact sheets are available on the HSC website in the following categories: Individuals with HD; Those At-Risk; Caregivers; Families; Professionals.
www.huntingtonsociety.ca

**EHDN's Standards of Care
for HD patients**

"The most comprehensive effort so far to document best practice in the clinical management of HD".



EUROPEAN HUNTINGTON'S DISEASE NETWORK

Step 1: Before your office visit, you and your care partner should identify the treatable HD symptoms that cause you the most trouble. Tell your doctor about your depression, anxiety, and insomnia; these are symptoms common in general practice that your doctor may already know how to treat. However, he or she may be less knowledgeable about other symptoms in HD like irritability, obsessive compulsive behaviors, and chorea. Telling your doctor about all of your symptoms will help him or her understand Huntington's disease and how these symptoms affect you and your family.

Step 2: Ask for treatment for all symptoms that cause trouble. Recently an international group of HD experts has developed treatment guides as an aid for you and your doctor specifically for those HD symptoms for there may be less experience. These treatment guides - called algorithms - provide information for treating chorea, irritability and obsessive-compulsive symptoms, and recommend medications that most general doctors prescribe frequently. Dose ranges are provided for those they may be less familiar with. If you are prepared for your visit a discussion about your symptom, and treatment can fit into your doctor's schedule, where the average time spent with a patient is about 16-18 minutes.

Step 3: Don't expect that one visit will result in the best treatment for your symptom. This is the tough part! Experts say it often takes several tries to find the best drug, dose of drug or drug combination that fits your unique situation. You won't get better if you don't keep seeing your doctor - on a frequent basis - for drug management. Don't give up or stop asking your doctor for help until you get the best drug treatment for all your treatable symptoms. You can be and HD symptom survivor!

Reprinted from WeHaveAFace.org.

Treatable Symptoms of Huntington's disease:

- Sadness and depression
- Anxiety
- Trouble sleeping
- Crankiness, impatience, easy irritability, anger
- Chorea movements
- Paranoid feelings
- Rumination, getting stuck on ideas, worry about the same thing over and over
- Aggressive actions, including damage to property, threatening to strike another person
- Thoughts of suicide or suicidal actions



HSC is a proud supporter of HDYO an International organization to help young people who are affected by HD. Visit www.HDYO.org

Staying Connected

Please visit our **website** and fill out our confidential contact information form to receive email communications from HSC. According to your preferences, we'll communicate with you in confidence by email about research findings, clinical trials, best practices of care, local and national events and happenings, volunteer opportunities, etc.

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